Current and Former Residents of Bellefontaine Habilitation Center:

Are People Better Off?

Brief Report Number 2
On the Well Being of People Affected by the Announced Closure of
Bellefontaine Habilitation Center:
Changes in Quality of Life
Among Those Who Moved and Those Who Stayed

Submitted to:

Missouri Planning Council for Developmental Disabilities

Submitted by:

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December, 2007
(Final Revisions April 2008)

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Appendix A: The Personal Life Quality Protocol

Introduction

This report contains the results of face to face visits, in mid-2007, with 41 people who were living at Bellefontaine Habilitation Center[1] in 2005. Our purpose was to find out whether their lives had gotten better since 2005, and if so, in what ways, and how much. We used several measures of quality of life with these individuals. The measures are all contained in the Personal Life Quality Protocol© contained here in Appendix A.

Governor Matt Blunt announced an intention to close Bellefontaine in January 2005:

> Under my budget, Missourians with developmental disabilities would enjoy a higher quality of life in a less restrictive environment, instead of in a state-operated institution. I support plans to expand private-sector community placements through closure of the state-operated Bellefontaine Habilitation Center. These actions will save the state $13.8 million and benefit Missourians with developmental disabilities.
> *Excerpt from Governor Matt Blunt's State of the State Address, January 26, 2005*

The present study was rapidly initiated by the Missouri Planning Council for Developmental Disabilities to answer one simple question: "Will these people be better off because of this new policy?" At the time of the announcement, approximately 350 people resided at Bellefontaine.

Bellefontaine has not, in fact, closed. It has, however, been reduced in size. Many people have moved – some to community homes, and some to other institutions. Most are still living at Bellefontaine. We obtained the consent of all the people we could, and of their closest allies (relatives, guardians, friends) to go

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[1] Also referred to as Bellefontaine or BHC.

visit them and measure qualities of their lives. We asked people to answer our questions with the help of anyone they selected – whoever knew them best. We also surveyed all the available families by mail, to find out what changes they had seen in their relatives' lives.

Because the number of people leaving Bellefontaine was not as large as expected, and also because not everyone granted consent, we could not visit, survey, and get life quality data from as many people as we would have liked. Nonetheless, the measures are valid and reliable, and the data were collected face to face with each individual. This is the best science one can do given the situation.

In the realm of public policy, we rarely have perfect data to make important decisions. In the present analysis, we wish we could have reached more of the people who moved, to get larger numbers. Nonetheless, even the numbers here represent about one out of five of the people who left Bellefontaine, and we do have a comparison group of people who did <u>not</u> leave Bellefontaine – and having a comparison group greatly increases scientific confidence. In the world of social sciences, these numbers and the methods are quite suitable for journal publication – a frequently used standard. In the end, there is no better information available to Missouri decision makers than the surveys of all consenting families plus the quantitative measurement of the qualities of life of consenting present and former residents of the Bellefontaine Habilitation Center.

As this report shows, the great preponderance of indications from the data lead to the conclusion that the movement of people from BHC to community homes had strongly positive outcomes. The movement of people from

Bellefontaine to other institutional settings had good outcomes, but not nearly as strong as for the movers to small community homes.

In our opinion, these outcomes should be weighed against public costs in the future. We should compare what society must spend to support people at BHC, other institutions, and community homes. Just as health professionals weight risks and benefits, public services must weight costs and outcomes.

Participants

We wanted to visit as many of the BHC residents as possible, no matter where they were living. This was complicated.

First, during the initial data collection at BHC, with state legal advice that a project such as this one was ethically <u>required</u> to monitor quality, a requirement for a full family consent process was added. BHC went to great effort to mail out a consent form we devised to as many family members and guardians as they could.[2]

In the end of this many months long process, we wound up with exactly 100 families and guardians giving consent for the participation of their relatives/wards in this project.

In the field, the fact of having family consent was sometimes not enough to assure immediate access. Many providers asserted their need to obtain additional clearances and permissions to permit our data collectors to have access to individuals and their records. They expressed various reasons for this, including privacy of the individual, privacy of the other individuals living in the setting, and resource limitations on staff time.

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[2] This number was between 200 and 270 – we were not allowed to see that list – rightly so, because before a family or guardian gave consent, we should not see their names or addresses.

In the Family Survey, which was mailed, we had 31 responses when done.[3] This was below, but not far below, the usual response rate to surveys of this type, which is about 40%.

For the face to face visits reported here, at the end of our field work, we had completed 41 data collection visits. Table 1 shows the way these broke down.

Table 1: Consent, Cooperation, and Final Data Collected

Living Situation	Consent Obtained	Provider Cooperation Obtained	Appointments Kept, Visits Completed
BHC	50	25	17
Community	33	20	16
Other Institutional	17	14	8
Total	100	59	41

A Note on Samples and Sampling Accuracy

A note on sample sizes and accuracy is in order here. "Margin of Error" is a term most often heard in the context of political polls. It has a very specific mathematical meaning, concerning how confident we should be in the findings of any survey, which is relevant to this Missouri survey of Bellefontaine residents. How "accurate" can a small sample, just 41 people, really be? In other words, is what we found for the 41 likely to reflect the experiences of all 250 people who lived at BHC at the time of the closure announcement? Another way to discuss the

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[3] Conroy, J., Ferris, C., Oppenheim, M, & Conroy, N. (2007, July). *Current and Former Residents of Bellefontaine Habilitation Center: A Survey of the Families and Guardians. Brief Report Number 1 On the Well Being of People Affected by the Announced Closure of Bellefontaine Habilitation Center: Changes in Quality of Life Among Those Who Moved and Those Who Stayed.* Research report Submitted to the Missouri Planning Council for Developmental Disabilities. Havertown, PA: Center for Outcome Analysis.

"Margin of Error" which is more intuitive and easier to interpret is called the "Confidence Interval." How close are the scores based on these 41 people to the scores we would get if we had surveyed all 250? In statistical jargon, *"The average scores we found for the 41 will be within 3 to 5 points of the actual values for the entire 250 --- 90% of the time."[4]*

To illustrate by example, we found the average Quality of Life score on our scale, which ranges from 0 to 100, for the 41 people in our sample, was 70. The statistical statement using the Confidence Interval approach is *"The odds are over 90% that the actual average Quality of Life score for all 250 people is between 66 and 74."*

In everyday life, this would be considered accurate. If we were in a room of 250 people, we would only have to weigh 41 people to get within a few pounds of the overall actual average weight.

We conclude that the accuracy of our sample of 41 people is enough to give high confidence that our findings are representative of all 250 Bellefontaine individuals. We can "generalize" from our survey to all the people who lived at Bellefontaine – and the chances that we will be "way off" are very slim.

These statistical notes, however, must be thought of in light of another problem called *"selection bias"* which means *"How can we be sure that the people and families that gave consent are the same in every way as the people and families that did not give consent?"* As in all of survey science, we cannot be sure of

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4 The exact confidence intervals will be slightly different for each scale.

this. The families/individuals that refused to consent <u>might</u> be different in some way(s) from the ones who did. This problem threatens political polls too – and in fact it threatens the accuracy of <u>all</u> surveys. Pollsters typically make thousands of phone calls to get a few hundred people willing to talk with them. Are the "willing to talk" people exactly the same as the ones who refuse? No one can be sure. This "selection bias" is a threat to all surveys and all samples – this Missouri one included. It is at least as great a threat to accuracy as small samples, and in many cases, considerably greater. Unfortunately, we cannot <u>get to</u> the families/individuals that chose not to consent to this Bellefontaine follow-up to check to see if their experiences were similar or different – because they refused. There is simply no way around this problem.[5] This leaves each of us trying to interpret the findings in this report, or in any survey, according to our own estimate of how similar or different the people who responded were to the people who did not respond.

Having given these important cautions, we who have been conducting surveys for many years are constrained to offer our own opinion, subjective as it may be, about the case of the Missouri Bellefontaine results. The biggest "selection bias" threat would have been that only the "happy" or "unhappy" families/individuals chose to consent. We cannot think of any reason for that to happen – usually, some of the "happy" **and** the "unhappy" are eager to have their voices heard. On balance, we believe the results from the 41 individuals will prove to be <u>very</u> close to the feelings of all 250, as the years pass and as we learn more during Bellefontaine's future changes.

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[5] Except in rare situations when we <u>can</u> get some information about the "non-respondents."

Description of the Participants

For the 41 people who were in our Participant group, the average age was 44, with a range from 19 to 67 years. There were 18 males and 23 females. Ethnicity was described as Caucasian/White for 27, African-American/Black for 11, and Asian or Pacific Islander for 3. Although labels for "level of intellectual disability" are somewhat antiquated, for descriptive purposes, it is useful to report that these labels were: Profound, 13 people; Severe, 8 people; Moderate, 7 people, Mild, 8 people; no label or unknown, 5 people.

Results 1: Qualities of Life for Three Groups

In order to determine if people who moved out of Bellefontaine are better off, we used a 14 item Qualities of Life Scale. This scale asks each person – or his or her surrogate --- to rate his/her quality of life "A Year Ago" and "Now." Ratings are given on 5 point scales, and cover 14 dimensions of quality of life. Within this scale 1 means "Very bad", 5 means "Very good", and 3 means "OK, In Between, So-So." Previous research with this same scale has revealed this scale is able to detect both significant and meaningful differences between groups of people as well as changes over time. While data were collected on everyone in terms of the current qualities of life, some respondents felt unable to make judgments about the individual's life "before". Therefore the data presented below will primarily focus on the current qualities of life.

The Quality of Life Scale indicates that people who moved into the community report statistically higher total qualities of life scores (78 points out of 100) than people who stayed at Bellefontaine Habilitation Center (62 points). While data for the people who moved to another institution suggest that their overall qualities of life score falls between the other two groups (70 points), these data should be viewed with caution given the small number of people in other institutions who responded to these questions (n=6). Higher or lower scores for any individual – i.e., also known as an outlier in social science research – from a small sample can drastically shift the overall average score.

Figure 1: Total Quality of Life "Now"
(out of 100 points)
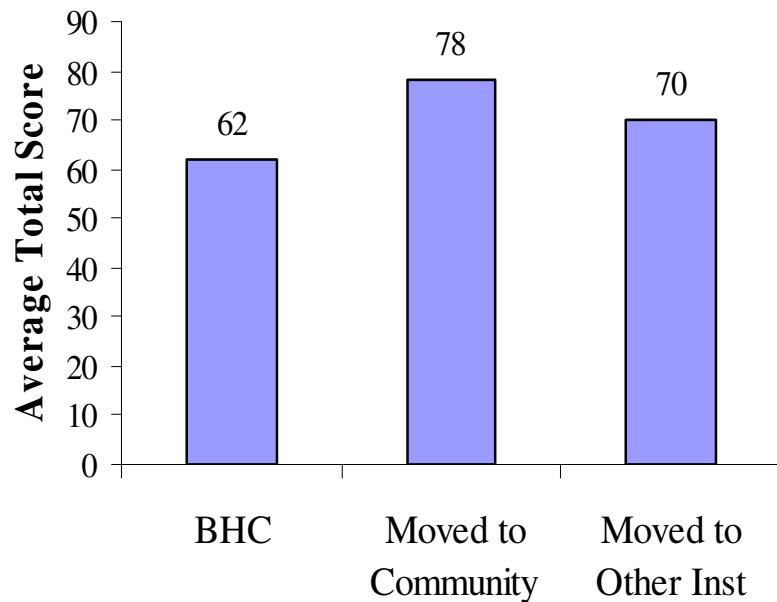
In terms of specific qualities of life (see Figure 2 following), those people who moved to the community reported statistically higher average scores in the following eight domains when compared to people who stayed at Bellefontaine Habilitation Center: (1) Running my own life, (2) Food, (3) Getting out, (4) Quality of life overall, (5) Family relationships, (6) "What I do all day," (7) Socializing/Seeing friends; and (8) Happiness. These data suggest that people who had been in the community for a relatively short period of time – one year, on average -- were experiencing substantial differences across a variety of life quality areas when compared to their peers who did not move into the community.

Figure 2: Specific Qualities of Life "Now"
(out of 5 points)

Domain	Moved to Community	BHC
Life Overall	4.6	3.5
Food	4.4	3.3
Happiness	4.4	3.7
Getting Out	4.2	3.1
Family	3.8	2.9
What I Do All Day	3.8	3.1
Running My Own Life	3.8	2.4
Social	3.7	3.0
Safety	4.7	4.4
Treatment by Staff	4.4	4.2
Comfort	4.3	4.1
Health	4.0	3.7
Health Care	4.0	3.7
Privacy	3.8	3.5

Significant Differences Between BHC & Movers

No Differences Between BHC & Movers

■ Moved to Community
☐ BHC
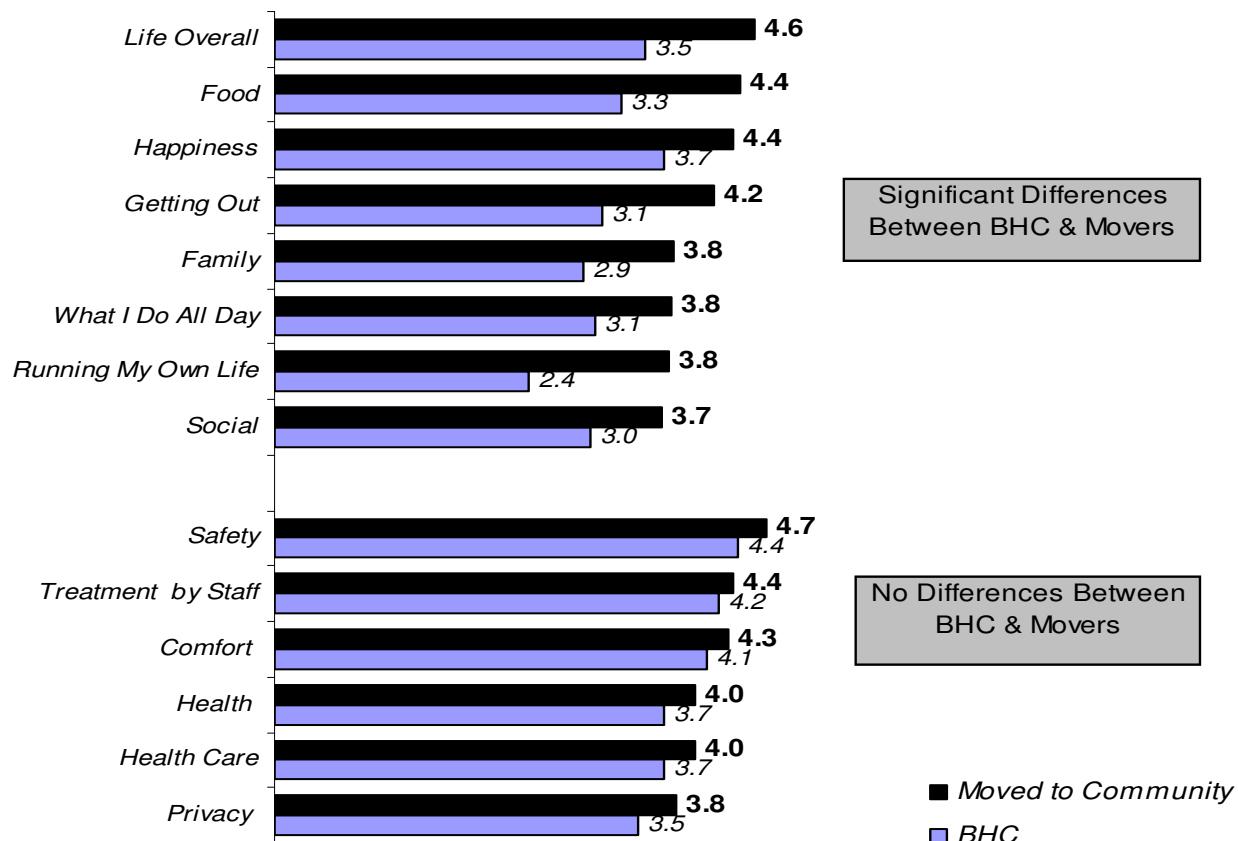
The largest single difference between the two groups was seen in the individual choice making. For the individuals remaining in Bellefontaine Habilitation Center "running my own life" had the lowest score across all 14 domains (2.4 out of 5 points) and was considerably below the next highest score of family relationships (2.9 points). In contrast, individuals in the community scored 3.8 points on average for this same domain, on an equal level to privacy, family relationships, "what I do all day," and socializing.

Finally, the data in Figure 2 indicates the people who moved to the community were experiencing both better qualities of life and greater consistency

in their lives. The average scores for those people ranged from 3.7 to 4.7 points, while people remaining in Bellefontaine Habilitation Center had life quality scores varying from 2.4 to 4.4. The "leveling" of the average scores across the 14 domains, especially when several domains are approaching the highest possible score – the 5 point ceiling –corroborates their assessment that life overall is better (4.6 out of 5 points).

Fortunately, these findings can be compared to what COA has found in other states – even to states in which a true "before and after" research design was used. In Missouri, the average overall quality of life score for BHC Stayers was 62 – for Movers it was 78. Is this anything like what has been seen in other studies? The answer is a strong Yes.

In California, where we tracked more than 2,000 people who moved from institution to community over the course of a decade, the average score went up from 71 to 80.[6] The institutional scores in Missouri are lower, but the community scores are about the same. In Indiana, scores on this scale increased from 66 to 78, very similar to the Missouri findings.[7] In Kansas, scores improved from 68 to 78.[8]

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[6] Conroy, J., Fullerton, A., & Brown, M. (2002, June). *Final Outcomes of the 3 Year California Quality Tracking Project*. Report Number 6 of the Quality Tracking Project for People with Developmental Disabilities Moving from Developmental Centers into the Community. Narberth, PA: Center for Outcome Analysis

[7] Conroy, J., & Seiders, J. (2000, May). *Outcomes of Community Placement at One Year For the People Who Moved From New Castle and Northern Indiana State Developmental Centers*. Report Number 6 of the Indiana Community Placement Quality Tracking Project. Submitted to the Division of Disability, Aging, and Rehabilitative Services, Indiana Family and Social Services Administration. Rosemont, PA: Center for Outcome Analysis

[8] Conroy, J. (1998, December). *Are People Better Off? Outcomes of the Closure of Winfield State Hospital.* Final Report (Number 6) of the Hospital Closure Project Required by Substitute House Bill 3047. Submitted to The Kansas Council on Developmental Disabilities and The Legislative Coordinating Council. Rosemont, PA: Center for Outcome Analysis.

All of these findings are so compellingly similar to the Bellefontaine data that we believe we should have very strong confidence that the Missouri findings are correct, reliable, and accurate.

Results 2: Choicemaking and Self-Determination for Three Groups

Since the early 1990s, one of the leading indicators of quality in supports and services for people with intellectual disabilities has been the extent to which choice and self-determination are permitted and encouraged. During our work on the national evaluation of self-determination for the Robert Wood Johnson Foundation, we created a scale that measures who controls life choices: paid staff, or the person and the person's freely chosen allies.

This scale, the Decision Control Inventory, is composed of 35 items, and is contained on one page. It has been shown to be sensitive and reliable. The 35 items can be combined into a single scale that reflects opportunities for choicemaking, and it ranges from 0 to 100. The scores obtained for the three groups are shown in the Figure below.

Figure 3: Choicemaking Scale Scores for the Three Groups
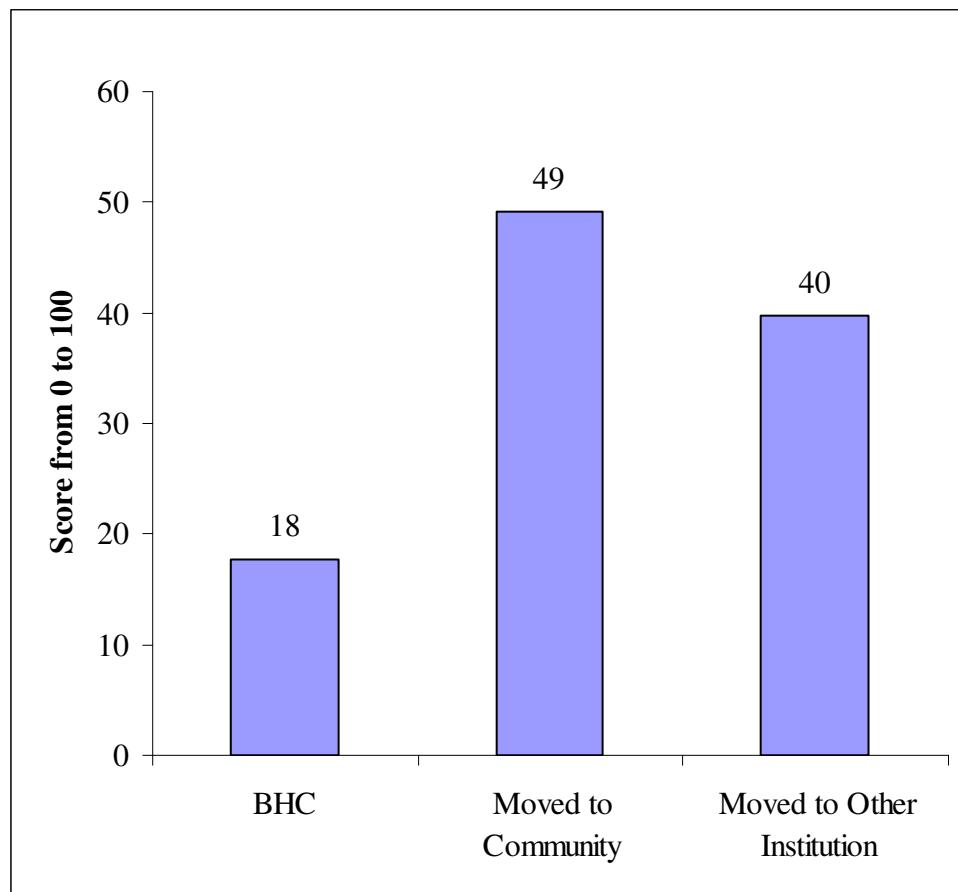
As the graph makes clear, the Movers to Community homes displayed the highest scores on this measure. This difference is highly significant by a standard statistical test, the Analysis of Variance ($F=23.579$, $df=2,35$, $p=.000$). This suggests superior quality in this critical dimension, particularly between the BHC Stayers and the Movers to Community.

Later, in Results 6, we will offer evidence that these Movers actually experienced a very large "Before and After" change when they moved from institution to community.

We can compare these findings to those of other states. COA has collected the same kind of choice-making data in several other states, particularly "before and after" people moved out of public institutions into community homes. For 179 people in California, the average score on this scale increased from 32 (in 1994, when they lived in institutions) to 46 in 2002 (after they had moved to community homes). The California data showed better choicemaking options in the institutions (32) than in Missouri's Bellefontaine (18) – and comparable options in community homes (46 in California, 49 in Missouri).[9] In Indiana, scores increased from 31 to 47 when people moved out of institutions.[10] In Kansas, the scores went up from 27 to 40 points.[11]

The fact that these results are so much "in line" with what we found in Missouri lends considerable scientific credibility to the Missouri work.

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[9]. Op. cit., COA California report.
[10]. Op. cit., COA Indiana report.
[11] Op. cit., COA Kansas report.

# Results 3: Integrative Activities for Three Groups

Integration, not segregation, of people with developmental disabilities, has been one of the gold standards of quality since the Kennedy era. The Harris polling organization developed a simple measure of this element of life in the 1980s, for its Surveys of Americans with Disabilities,[12] and we adapted some of that work for the National Consumer Survey of 1990[13] and many studies since then. It is a simple count of how often people "get out" each month into 16 kinds of integrated settings – settings where any citizen might be – not settings restricted to people with disabilities. The kinds of activities include going to a movie, going to a restaurant, visiting a friend's home, attending a service at a house of worship, and so on – the kind of things any citizen might go out to do.

The survey scale counts how many of each of those activities happened in the past month – and then we add them up. We know that the national average for non-disabled citizens is about 50 such activities per month – roughly 12 per week. The results for our three groups are shown in Figure 4.

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[12] Taylor, H., Kagay, M., & Leichenko, S. (1986). The ICD Survey of Disabled Americans. Conducted by Louis Harris and Associates. New York: The International Center for the Disabled, and Washington, DC: National Council for the Handicapped.

[13] Conroy, J., Feinstein, C., Lemanowicz, J., Devlin, S., & Metzler, C. (1990). The report on the 1990 National Consumer Survey. Washington DC: National Association of Developmental Disabilities Councils.

Figure 4: Integrative Activities Per Month for the Three Groups

Integrative Activities

(Bar chart — Y-axis labeled "Events Per Month" from 0 to 30; three bars labeled BHC = 9, Moved to Community = 24, Moved to Other Institution = 8)
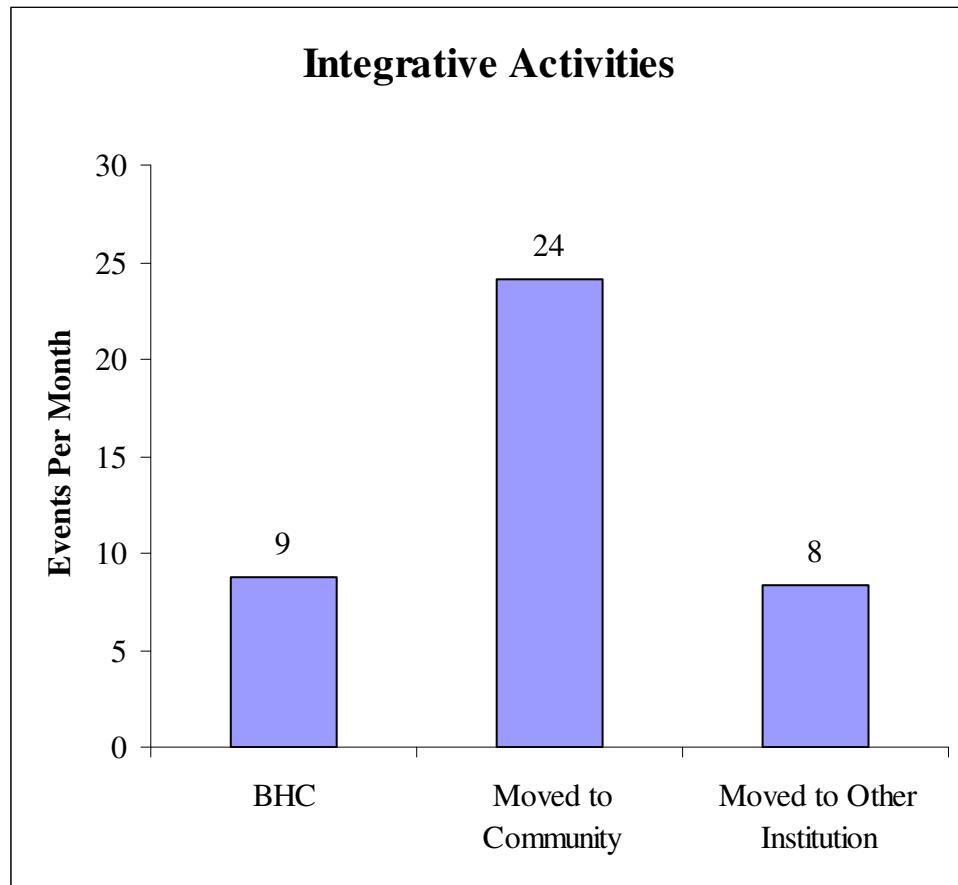
First, the graph shows that all three groups fall far below the "average citizen" level of about 50 integrative outings per month. Secondly, the graph shows a fairly large difference across the three groups. The differences are highly statistically significant ($F=7.334$, $df=2, 36$, $p=.002$).

The interpretation of the graphs is that people at BHC tended to "get out" about 9 times a month – the Movers to Community more than doubled that, at 24 events per month – while the Movers to Other Institutions were more like the BHC residents, at 8 outings per month. Again, these figures are interesting in comparison to non-disabled citizens who average about 50 events per month.

Insofar as integration is a value, the Movers to Community seem to be the "best off" in this area.

For further comparison, COA fortunately has the same kind of data from institutional residents and from "Movers to Community" in many other states. Here is a sampling of findings:

Table 2
Integrative Activities Finding for Institution and Community in Seven States

	People Living in Institutions	People Who Moved to Community Homes
New Jersey	18	47
Connecticut	17	35
Kansas	3	31
California	14	30
Indiana	11	30
Oklahoma	11	28
North Carolina	7	25
Missouri	8 or 9	24

The ability to compare data across states can be very powerful. This table suggests a need for increased attention to "getting out" into integrative activities for all the Bellefontaine group members in Missouri – whether they left or not, more can be done.

Results 4: Individualized Support Practices for Three Groups

The Individualized Practices Scale has been in use in various forms since the 1970s. It embodies the notion that people should be treated as unique individuals, rather than as groups with the "one size fits all" services approach. The scale has been used in dozens of studies over the years.[14]

Once again, the Movers to the Community show the highest scores on this dimension of quality, as seen in Figure 5.

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[14] King, R., Raynes, N., & Tizard, J. (1971). Patterns of residential care: Sociological studies in institutions for handicapped children. London: Routledge and Kegan Paul.

Figure 5: Individualized Practices Scale for Three Groups
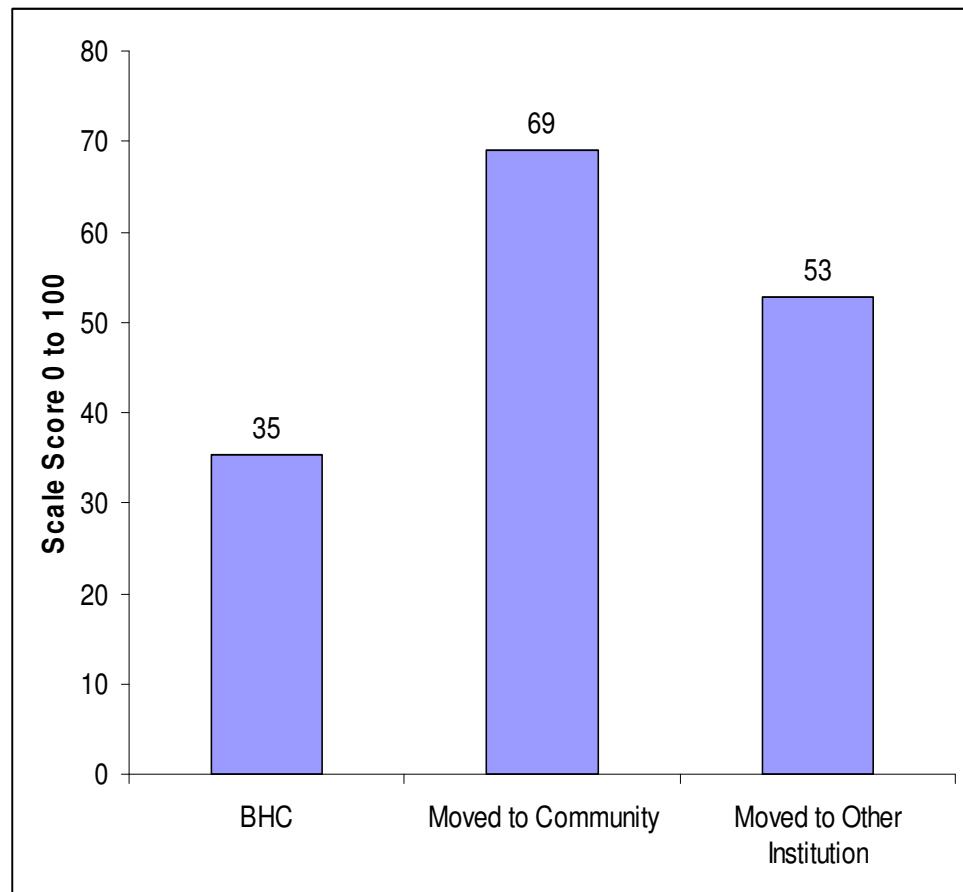
The differences among the groups are highly significant (F=24.957, df=2, 34, p=.000).

Results 5: Person-Centered Planning for Two Groups

For a few of the outcome scales, respondents and their helpers were often unable to report some areas of quality. Usually this was caused by "not knowing the person well enough" or "not having enough time to judge." This was particularly true for our measure of Person-Centered Planning among the Movers to Other Institutions. Thus, for this measure, we could only analyze data for two groups – the Bellefontaine Stayers and the Movers to Community. Figure 6 shows the comparison of these two groups on this measure.

Figure 6: Elements of the Planning Process Scale for Two Groups
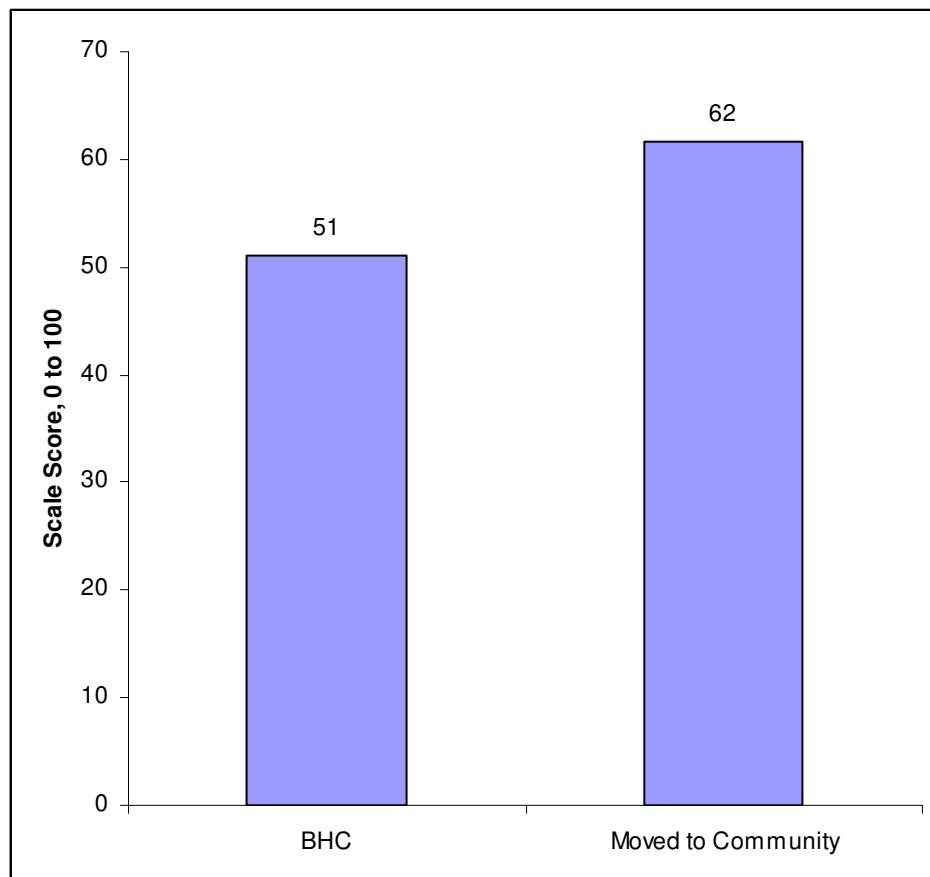
The graph makes it clear that the Movers to Community experienced stronger "Person-Centered" practices in their individual planning processes. This should come as no surprise, because the people in the community are in so much smaller settings. The difference is highly significant (t=2.371, 24.3 df, p=.013).

Results 6: Progress Toward Individual Goals for Two Groups

For each person visited, we collected a list of their top five individual program goals – then asked for a rating of the degree to which each one had been achieved. The ratings ranged from Major Regression, through No Progress, up to Major Progress. Once again, these ratings were all combined into a single numeric measure of "goal attainment," which could range from 0 to 100. The Movers to Community showed a higher overall rating on this scale than the BHC Stayers.

Figure 7: Progress Toward Individual Program Goals for Two Groups
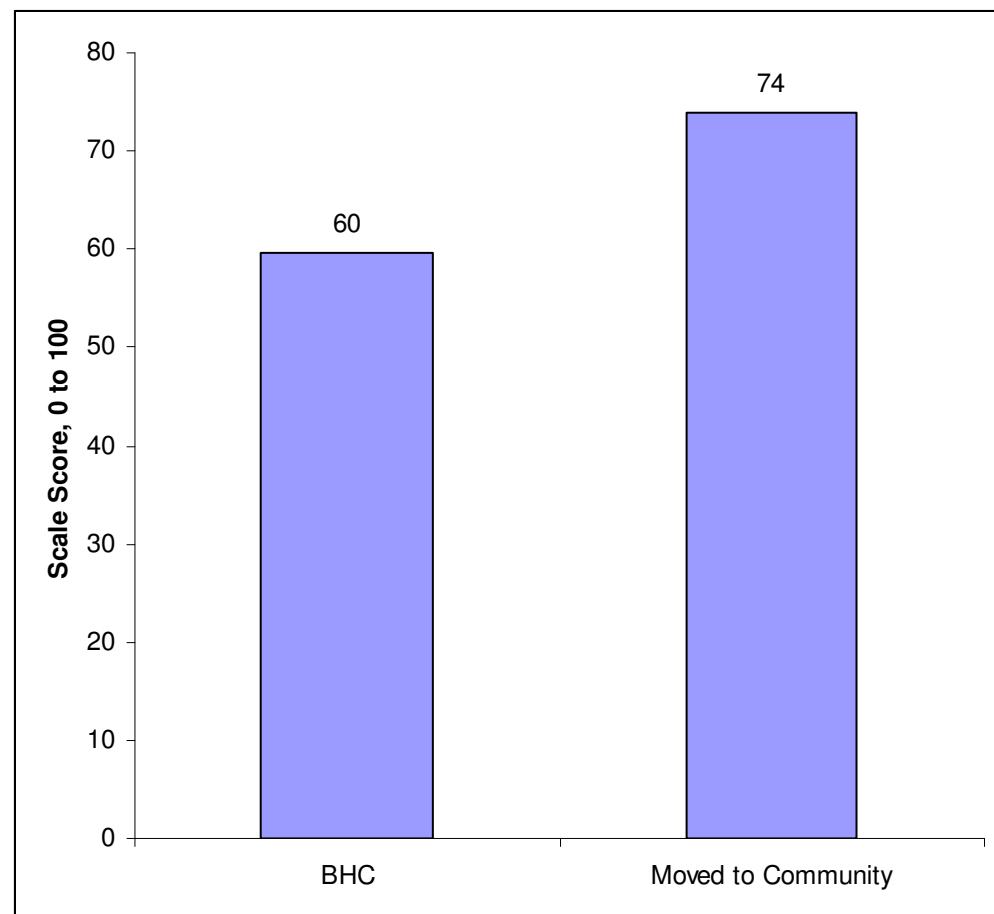
It is obvious that making progress toward one's individual program goals is an important element of service quality, and an outcome as well. In this regard, the Movers to Community surpassed the people who remained at BHC, and the difference was significant (t=2.12, 18.5 df, p=.020).

Results 7: Results: Memory of "Then and Now"

When possible, it is best to visit people and measure quality of life <u>before</u> they leave one home[15] – and then visit and measure again <u>after</u> they go to the new home. Then we can best tell whether their lives have gotten better or worse. Like starting a weight loss program, it is important to know your starting point, so you can see your progress. This is called "Pre and Post" measurement in research jargon. In everyday English, it's called "Before and After."

We tried to do that in this study – visit people before and after they moved. We began field work at BHC, to get the "Before" data, but had to stop for many months in order to comply with a requirement, imposed after we began, to obtain full consent from person, family, and guardian. By the time this was done, many people had already left BHC. We could not get the "Before" data for them.

Fortunately, we had measurement instruments devised for just such a situation which has been used in large-scale studies across the country. The approach of these instruments was based on memory. The following few lines give an example of the Quality of Life Then and Now instrument, which is fully shown in Appendix A.

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[15] This step is called "getting baseline data" in research jargon.

SAMPLE
Qualities of Life, Then and Now
(To Be Answered by the Person <u>or</u> Whoever Knows the Person Best)
Copyright © J.W. Conroy 1994, 1996, 1997, 2003

Ask the person to rate the qualities of his/her own life "THEN" and "NOW."

**THEN means back at Bellefontaine; if still at the Bellefontaine, "THEN" means 2 years ago.
NOW means within the past 4 weeks.**

THEN 1 Very Bad 2 Bad 3 OK 4 Good 5 Very Good	NOW 1 Very Bad 2 Bad 3 OK 4 Good 5 Very Good	**Life Area**
		1 Health
		2 Running my own life, making choices
		3 Family relationships

Since this approach relies on memory, traditional social science wisdom might conclude that it is less accurate than actual "Pre and Post" or "Before and After" data collection. It is somewhat like trying to gauge the progress of a weight loss program by memory. While a scale can tell us exactly how many pounds we have lost as an absolute value, relying on memory can provide an accurate assessment of how we <u>feel</u> about our success (or lack, thereof). If asked directly, we would probably under or over-estimate exactly how much weight we've lost. Yet if asked for a subjective assessment, we could provide a generally accurate opinion of the change in our bodies.

Our research using the "Memory of Then and Now" method has turned out to yield results very similar to the true "Before and After" method in large scale multi-year studies in California and Michigan (with people with developmental disabilities), New York (with people with Alzheimer's), and Illinois (with foster children). Our past research, has also demonstrated that it is important to look

beyond the values derived from each scale and apply statistical tests to these data. By using standard and generally accepted statistical tests on these data we can identify significant differences either between groups or over time which are real and not due to chance alone.

With that limitation in mind, we present the findings from the five scales that were constructed to include "Memory of Then and Now" data

1. Qualities of Life	Quality of life in 14 areas
2. Decision Control Inventory	Opportunities to make life choices in 35 areas
3. Current Abilities	Self-care abilities in 14 areas
4. Challenging Behavior	Aggressive or self-injurious behaviors in 20 areas
5. Integrative Activities	Activities among non-handicapped citizens in 16 areas

Although we have analyzed all of these scales item by item, we present here only the summary scales. That is, for the Qualities of Life Then and Now, we combine all 14 items into one simple overall score of perceived quality of life. This score again ranges from 0 to 100. The other scales are treated the same way.

In addition, we only present the findings for the Movers to Community homes here. For the Movers to Other Institutions, it was usually decided by the people and their helpers that there was not enough knowledge of the former situations to report anything about the past. (Interestingly, peoples and staff in community settings felt that they knew a great deal about the previous home and life situation.) Hence we have left out the Movers to Other Institutions in this chapter. We have also left out the Stayers at BHC because the "THEN" data were not collected in our initial baseline data collection – since we thought we would be able to complete a true "Pre-Post" design.

Restricting the analysis only to the 16 Movers to Community Homes who provided both "Then" and "Now" data, produces the simple results table below.

Table 3: Outcomes According to "Memory of Then and Now" Method

	Then	Now	# People with both "Then" and "Now data"	Statistical Significance*
Quality of life in 14 areas	45	74	13	0.004*
Opportunities to make life choices in 35 areas	32	55	12	0.005*
Self-care abilities in 14 areas	70	71	13	0.143
Aggressive or self-injurious behaviors in 20 areas			3	0.370
Activities among non-handicapped citizens in 16 areas	18	16	12	0.400

* These statistical significance figures were computed using the Paired-t test for matched pairs – but because of small Ns, they were also run with the nonparametric Wilcoxon Signed Ranks test, with essentially the same results.

According to this "Memory Then and Now" analysis, the Movers to the Community experienced a dramatic increase in perceived overall Quality of Life from 45 points to 74 out of 100. This reached strong statistical significance – the chances of such large change happening by chance were about 4 in 1000 (0.004).

Secondly, the Memory method reveals a tremendous increase in opportunities to make life choices – almost doubling from a score of 32 to 55. Again, this was highly statistically significant.

When such powerful significance arises from small sample sizes, the best conclusion we know of is that "these effects must be quite large and are not due to random chance."

We do not see a significant increase in self-care abilities among the 13 Movers for whom we had complete data. It appears that the Movers have not actually gained new skills in adaptive behaviors and activities of daily living thus

far. The data on aggressive or self-injurious behaviors were too often missing to be reported, so we have no conclusions there.

As for integrative activities, there is no increase, and this is a mild surprise – because the Movers to Community homes are higher than the Stayers, and higher than Movers to Other Institutions – and also because we have seen increased integration in past studies. While we do not have a definitive explanation for the lack of increase in the integration scores so far for this small sample of people, we can theorize that the people who moved to the community had more opportunities for integrative experiences before they left BHC than the Stayers – one possibility is that they had more family involvement which included visits and outing.

Summary

The studies in this series were intended to find out whether the people affected by the plan to close Bellefontaine would be "better off" because of the policy change. Although the closure policy was later abandoned, and Bellefontaine remains open, many people did move to other settings. We obtained reasonably good samples of those "Movers," and compared the qualities of their lives and services to those of the "Stayers." The data clearly implied that the Movers to Community Homes benefited the most from all the changes.

We divided the participants in this tracking project into three groups:

- Those who stayed at Bellefontaine;
- Those who moved to small community homes;
- Those who moved to other large institutional settings.

In nearly every comparison we could perform, the quality of life, and the changes in the quality of life, were superior for the people who moved from Bellefontaine to community homes.

In spite of the limitations on this study, which included smaller numbers of participants than we had hoped for, there is good reason to treat these findings with considerable confidence. Not only are these the best data known to exist, but they are scientifically defensible from the points of view of methodology, instruments, and sampling theory.

Moreover, we have provided data from several other large scale studies, using the exact same instruments – and we have seen that the results obtained in

other states are compellingly similar to those we have found in the Bellefontaine study. The fact that the other studies were true "before and after" research designs only heightens our confidence in the Missouri work, which relied on group comparisons and memory.

No study being perfect, we offer this report as a good initial analysis of a process that will probably continue: the exodus of people out of Missouri's large institutions and into small, family-like, community homes and apartments located in typical residential neighborhoods.

Appendix A

Personal Life Quality Protocol

Personal Life Quality Protocol

Missouri Version 1.2
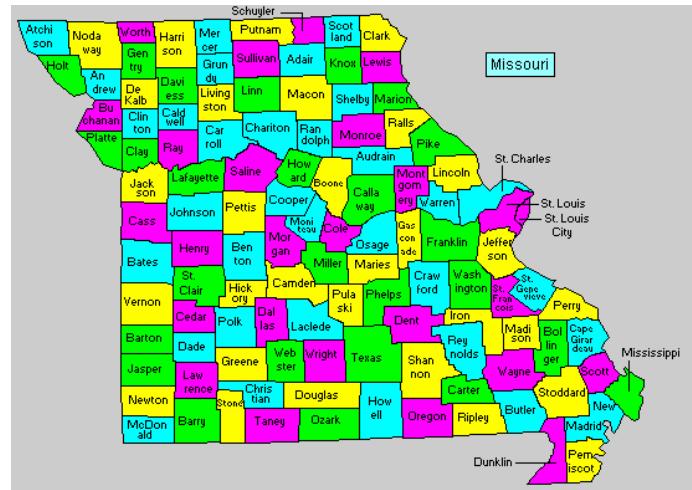
For Tracking the Individual Impacts
Of Moving from Habilitation Centers to Communities

Personal Life Quality Protocol

Missouri Institution-To-Community Version 1.1
Designed for the Missouri Quality Tracking Project, 2005-2007
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Individual Information

<u>**Consumer:**</u>

1. _____ 2. _____ 3. _____
         First Name   M.I.   Last Name

4. __ __ __ - __ __ - __ __ __ __ 5. _____ 6. _____
    Social Security Number   Local Consumer Unique ID   Consumer Phone Number

<u>**Service Providers:**</u>

7. _____ 8. _____
    Habilitation Center or Community Provider   Code

9. _____
    Name of Agency that Provides Case Management, Support Coordination, Service Coordination

10. _____ 11. _____
    Name of Residential Supports Provider   Provider Phone Number

12. _____
    Person's Complete Mailing Address, Including Apartment #, Line 1

13. _____
    Person's Complete Mailing Address, Including Apartment #, Line 2

14. _____ 15. _____ 16. _____
    City or Town   State   Zip Code

17. _____
    Home Site Code, AFC, If Any

<u>**Survey Respondents:**</u>

18. _____ 19. _____
    Primary Respondent's Name   Title or Relationship to Person

20. _____ 21. _____
    Name of Person Completing This Protocol   Title or Relationship to Person

22. ____ ____ / ____ ____ / ____ ____
    Today's Date

General Instructions

This package is composed of several brief scales and measures. These brief scales will let us find out whether each person involved in self-determination has changed in:

- Individual planning process and person-centered planning
- Individual goals and progress toward them
- Integrative experiences
- Choice and control over life decisions
- Behavior – both abilities and challenges
- Perceived qualities of life

In order to complete the package, you must have access to the person, and if the person wants or needs assistance in completing the difficult items, whoever knows the person best on a day to day basis.

Nearly all of the items ask you to write down a number. Each number means something, and each page tells you the "codes" that tell what each number means. All of these numbers will be combined to figure out whether people's lives have really changed after leaving a Habilitation Center. This will tell us something very important: Does movement to the community really result in enhance individual treatment, better services, and improved qualities of life and satisfaction? (In a separate effort, we will be studying costs, too.)

After some practice sessions, you will probably be able to complete this package within the range of 60 to 120 minutes.

Informed Consent Form
For Missouri Quality Tracking Project
On the Impacts of Moving from Institution to Community

I am _____, and I am working on a project to find out what happens to people when they leave Habilitation Centers to go to new community homes.

Today, I am visiting and collecting information about your/his/her situation and qualities of life. The company I work for is the Center for Outcome Analysis. We are funded by the Missouri Planning Council for Developmental Disabilities. This Project is approved by the Missouri Department of Health, Division of Mental Retardation and Developmental Disabilities.

But your permission is the important thing. I want to ask you for your "informed consent" for me to interview you and people close to you. That means I have to explain what I'm doing, and then ask you if it's OK.

People all over the county want to know whether leaving institutions for new homes in regular neighborhoods is a good idea. Does it make life better? Are people happier? Do folks get all the services and supports they need? What about getting out, having friends, money, making choices? Do individual plans really get at the things people want and need?

To find out about all this, we are visiting with everyone who is planning to move out of Habilitation Centers from January 2005 to January 2007. We're going to ask you and the people who are closest to you to tell us about your life right now. Later, after you've been in your new home about a year, we will come to you in person and find out how you're doing.

To collect all the information, we need to talk with you and the people closest to you for about an hour or two. We can break that time up and take breaks. We'll also want to be allowed to look at your Individual Plan and your paper records.

We don't know of any risk or danger that could come from this interview. On the other hand, doing these interviews could help a lot of other people. Everything we learn about you will be kept private. We'll only put averages from lots of people into our reports. No one will ever be told exactly what you say to me – unless you ask me to tell someone.

If you don't want to do this, it's OK. There won't be any problem for you, your family, your providers, or anybody. You can agree to work with us now if you want – but then you can stop at any time with no problem. This is completely your choice.

So, will you agree to be part of this work to find out about how community living works for you?

_____
Signature If Yes (Check below if surrogate signs or cosigns)

☐ Check Here if Surrogate Signed or Cosigned

☐ Or Refused Check Here

Any questions you may have about this work can be directed to:
Jim Conroy
Center for Outcome Analysis
426B Darby Road
Havertown, PA 19083
610-668-9001
jconroycoa@aol.com

Individual Descriptive Information

1. DATE OF BIRTH

____ ____ - ____ ____ - ____ ____
   Month   Day   Year

2. AGE

_____

3. GENDER

         1 Male
_____   2 Female

4. PRIMARY ETHNICITY

         1 Native American
         2 Asian or Pacific Islander
         3 African American or Black
_____   4 White/Caucasian
         5 Hispanic
         6 Multiracial
         7 Unreported

5. LEGAL STATUS

         1 Parent or other relative is full guardian
         2 Parent or other relative is limited guardian (including conservatorship)
_____   3 Unrelated person is full guardian
         4 Unrelated person is limited guardian (including conservatorship)
         5 Person has no guardian or is own guardian, not adjudicated incompetent

6. LEVEL OF MENTAL RETARDATION LABEL (IF ANY)

         0 Profound
         1 Severe
_____   2 Moderate
         3 Mild
         4 Mental retardation present, but no level labeled
         9 Not labeled with mental retardation

7. COMMUNICATION SUPPORTS NEEDED: Does this person need any of the following supports in order to be interviewed? (CHECK ALL THAT APPLY.)
 0=No
 1=Yes
_____ A. Verbal language interpreter
_____ B. Signing interpreter
_____ C. Computer
_____ D. Language board
_____ E. Symbol cards
_____ F. Other adaptive device

8. OTHER DISABILITIES
0 = No disability
1 = Some disability
2 = Major disability
_____   A.   Ambulation (Walking)
_____   B.   Autism
_____   C.   Behavior: Aggressive or Destructive
_____   D.   Behavior: Self Abusive
_____   E.   Brain Injury
_____   F.   Cerebral Palsy
_____   G.   Communication
_____   H.   Dementia (Including Alzheimer's Disease)
_____   I.   Health Problems (Major):_____
_____   J.   Hearing
_____   K.   Physical Disability Other Than Ambulation:_____
_____   L.   Seizures
_____   M.   Substance Abuse: _____
_____   N.   Vision
_____   O.   Other (s) _____

9. Is this person participating in a Self Determination Project?
        0 No   (Skip next question)
_____   1 Yes

10. For <u>about</u> how many months so far? (We recognize that a "beginning date" is very hard to define.)

_____ months

11. In the words of the person, or someone close to the person, WHY did he/she get involved in the self-determination efforts?

Living Situation and History

1. CURRENT TYPE OF HOME
       1 Own Home
       2 Parents' or Other Relatives' Home
       3 Supported Living in Community (not a group home)
       4 Supervised Community Residence (Group Home)
_____ 5 Foster Home, non-relatives
       6 Foster Home, relatives
       7 Nursing Home
       8 Developmental Center
       9 Other _____

2. DID YOU CHANGE HOMES AFTER GETTING INVOLVED IN SELF-DETERMINATION?
       1 No
_____ 2 Yes

3. IF YES, WHAT WAS YOUR PREVIOUS TYPE OF HOME? (Use codes from #1 above.)

_____

4. WHAT KIND OF HOME DO YOU THINK YOU'LL BE LIVING IN 5 YEARS FROM NOW?
       0 SAME AS NOW
       1 Own Home
       2 Parents' or Other Relatives' Home
       3 Supported Living in Community (not a group home)
       4 Supervised Community Residence (Group Home)
_____ 5 Foster Home, non-relatives
       6 Foster Home, relatives
       7 Nursing Home
       8 Developmental Center
       9 Other _____

5. HOW MANY PEOPLE LIVE IN THIS HOME? (If this is a community home, then please define home as a distinct **mailing address**.)

5A. _____ People with disabilities (<u>including</u> this person)

5B. _____ People without disabilities (unpaid cohabitants, including friends, parents, other family members.)

5C. _____ Paid staff who live here (paid cohabitants)

6. HOW MANY STAFF WORK IN OR AT THIS HOME? (Counting all shifts, and only count staff who are physically present at the home regularly, not staff who make phone contacts or staff who monitor alarm devices.)

6A. _____ Full Time Staff (Enter 0 if none or 99 for NOT APPLICABLE, such as Independent Living)

6B. _____ Part Time Staff (Enter 0 if none or 99 for NOT APPLICABLE, such as Independent Living)

Elements of the Planning Process, Before and Now

Ask the person to rate each element "BEFORE" and "NOW." For the Self-Determination Project, "BEFORE" means just before this person became involved in Self-Determination – or as long ago as the person or the person's friend can recall.

BEFORE	NOW	
1=Not at all 2=Somewhat 3=Half 4=Mostly 5=Completely 9=Don't know, Not applicable	1=Not at all 2=Somewhat 3=Half 4=Mostly 5=Completely 9=Don't know, Not applicable	
AB	AN	How were you involved in the planning process for this person? (If Not at all, skip the rest of this table.)
BB	BN	Does the planning process make strong efforts to understand the focus person's long term dreams? (As opposed to short term goals set by others.)
CB	CN	Does the planning process emphasize building a network of supports from informal, unpaid, or general community sources?
DB	DN	Are the meetings comfortable and relaxed for the focus person? (As opposed to formal and "official.")
EB	EN	Are planning sessions scheduled as needed? (As opposed to a regular set schedule, such as annually.)
FB	FN	Is the planning process defined or regulated by a set of standards, licensing requirements, rules, or laws, or regulations?
GB	GN	Does the planning process encourage creativity, new ideas, different ways of thinking?
HB	HN	Does the planning process allow for conflicts and disagreements, and try to resolve them?
IB	IN	Is the planning process flexible, allowing for changes in approach when things do not work?
JB	JN	Does the person have ultimate authority? (Could he or she overrule the entire group on an issue, within safety limits?)
KB	KN	Did the planning process emphasize cooperation among all participants? (As opposed to professional authority.)
LB	LN	Does the planning process emphasize the person's relationships? (As opposed to emphasizing skill development, or behavior, or services.)
MB	MN	Does the planning process take money into consideration? (Does the group discuss what supports cost, and what alternatives there are?)
NB	NN	Does the planning group have control over the resources (money) devoted to supporting the focus person?
OB	ON	Do the unpaid group members have the real power? (As opposed to paid staff and professionals.)
PB	PN	Do you consider this plan to be "person-centered"?

1. PLAN DATE: When was this plan last approved and/or signed, or otherwise put into effect?

_____ / _____
  Month   Year

2. PLANNING MEETINGS: About how many times did the planning group get together in the past year to create this plan?

_____ planning meetings in the past year?

3. APPROXIMATE AVERAGE LENGTH OF A PLANNING MEETING:

_____ hours per session

4. NUMBER OF PLANNING PARTICIPANTS: How many people participated/are participating in the person's planning efforts right now?

_____ members

PLEASE CATEGORIZE THESE CURRENT **PLANNING PARTICIPANTS**:

5. BEFORE SELF-DETERMINATION

Number of Paid Personnel	Number of Unpaid Relatives	Number of Paid Relatives	Number of Unpaid Non-Relatives
A	B	C	D
_____	_____	_____	_____

6. NOW, DURING SELF-DETERMINATION

Number of Paid Personnel	Number of Unpaid Relatives	Number of Paid Relatives	Number of Unpaid Non-Relatives
E	F	G	H
_____	_____	_____	_____

7. Case Manager Contacts Per Month (approximate, average) Before Self-Determination and Now:

_____   _____
Then (Before)   Now (During)

Decision Control Inventory, Before and Now

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Ask the respondent to say who <u>actually</u> makes decisions in each area as shown, from 0 to 10. If decisions are made entirely by PAID PERSONNEL (program staff, Case Manager, agency officials, doctors, etc.), enter "0" for that area. If decisions are made entirely by the PERSON AND/OR TRUSTED FRIENDS, RELATIVES, ADVOCATES, etc., enter "10." If decisions are equally shared, enter "5." Ask the person to rate each area "BEFORE" and "NOW." For the Self-Determination Project, "BEFORE" means just before this person became involved in Self-Determination – or as long ago as the person or the person's friend can remember.

WHO MAKES DECISIONS?

   0---1---2---3---4---5---6---7---8---9---10

Paid   **Unpaid (Person and/or Trusted Friends, Relatives, Advocates**

BEFORE	NOW	FOOD
1PB	1PN	What foods to buy for the home when shopping
2PB	2PN	What to have for breakfast
3PB	3PN	What to have for dinner
4PB	4PN	Choosing restaurants when eating out
		CLOTHES AND GROOMING
5PB	5PN	What clothes to buy in store
6PB	6PN	What clothes to wear on weekdays
7PB	7PN	What clothes to wear on weekends
8PB	8PN	Time and frequency of bathing or showering
		SLEEP AND WAKING
9PB	9PN	When to go to bed on weekdays
10PB	10PN	When to go to bed on weekends
11PB	11PN	When to get up on weekends
12PB	12PN	Taking naps in evenings and on weekends
		RECREATION
13PB	13PN	Choice of places to go
14PB	14PN	What to do with relaxation time, such as choosing TV, music, hobbies, outings, etc.
15PB	15PN	Visiting with friends outside the person's residence
16PB	16PN	Choosing to <u>decline</u> to take part in group activities
17PB	17PN	Who goes with you on outings?
18PB	18PN	Who you hang out with in and out of the home?
		SUPPORT AGENCIES AND STAFF
19PB	19PN	Choice of which service agency works with person
20PB	20PN	Choice of Case Manager
21PB	21PN	Choice of agency's support persons/staff (N/A if family)
22PB	22PN	Choice of support personnel: option to hire and fire support personnel
		ECONOMIC RESOURCES
23PB	23PN	What to do with personal funds
24PB	24PN	How to spend residential funds
25PB	25PN	How to spend day activity funds
		HOME
26PB	26PN	Choice of house or apartment
27PB	27PN	Choice of people to live with
28PB	28PN	Choice of furnishings and decorations in the home
		WORK OR OTHER DAY ACTIVITIES
29PB	29PN	Type of work or day program
30PB	30PN	Amount of time spent working or at day program
31PB	31PN	Type of transportation to and from day program or job
		OTHER
32PB	32PN	Express affection, including sexual
33PB	33PN	"Minor vices" - use of tobacco, alcohol, caffeine, explicit magazines, etc.
34PB	34PN	Whether to have pet(s) in the home
35PB	35PN	When, where, and how to worship

Qualities of Life, Before and Now
(To Be Answered by the Person <u>or</u> Whoever Knows the Person Best)
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Ask the person to rate the qualities of his/her own life "BEFORE" and "NOW." For the Self Determination Project, "BEFORE" means just before this person became involved in Self Determination --- OR as long ago as the person and/or the person's friend can remember.

BEFORE 1 Very Bad 2 Bad 3 OK 4 Good 5 Very Good		NOW 1 Very Bad 2 Bad 3 OK 4 Good 5 Very Good		**Life Area**
	1B		1N	**1 Health**
	2B		2N	**2 Running my own life, making choices**
	3B		3N	**3 Family relationships**
	4B		4N	**4 Seeing friends, socializing**
	5B		5N	**5 Getting out and getting around**
	6B		6N	**6 What I do all day**
	7B		7N	**7 Food**
	8B		8N	**8 Happiness**
	9B		9N	**9 Comfort**
	10B		10N	**10 Safety**
	11B		11N	**11 Treatment by staff/attendants**
	12B		12N	**12 Health care**
	13B		13N	**13 Privacy**
	14B		14N	**14 Overall quality of life**

Individual Budget Information
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1. _____ months About how long has this person had an individual budget?

2. $_____ per year About how much is in the person's individual budget annually?

3. HOW ARE FUNDS SPENT? Try to obtain rough estimates of how these individual budget funds are spent. If the person is living in a group situation, try to figure out how much this person's supports costs (often you simply divide by the number of people).

	3A. Housing (including rent, mortgage, utilities, food, household supplies, etc.)
	3B. Personal support in the home (staff, personal care attendants, home health aides, support coordinators, etc.)
	3C. Transportation of all kinds
	3D. Supported work, education tuition, adult day activity, community experience program
	3E. Therapies (psychological, physical, occupational)
	3F. Recreation, entertainment, vacations, buying leisure items such at televisions, stereos, exercise equipment, or luxuries
	3G. Other

4. In what ways does this person and his/her self-determination allies now control his/her individual budget?
   0=Not at all
   1=Some
   2=Complete control
   _____ 4A. Took part in the original development of the budget.
   _____ 4B. Keeps track of how budget is being spent.
   _____ 4C. Decides how much personal assistance s/he wants each week.
   _____ 4D. Signs and/or authorizes payments to providers of supports.
   _____ 4E. Decides how their individual budget will be modified, with or without assistance.
   _____ 4F. Selects and/or directs a fiscal intermediary to distribute pay or other resources.

5. Please BRIEFLY describe who acts as fiscal intermediaries, and what function(s) they perform on the person's behalf., e.g., payroll for support personnel.

6. Were there things or services or supports that you and your allies have been able to purchase via self-determination that you probably could not have gotten otherwise? One example is fine. Why did you buy that? What did it do for you?

Health Information

1. GENERAL HEALTH: In general, how is this person's health?
        1 Very Poor
        2 Poor
_____   3 Fair
        4 Good
        5 Excellent

2. ILLNESS IN PAST 28 DAYS:

_____ Number of days of restricted activity because of illness

3. DOCTOR VISITS: About how many times has the person been seen by a doctor in the <u>past year</u>?
_____ 3A. About how many visits were for acute illness?
_____ 3B. About how many visits were for normal preventive care?
_____ 3C. About how many visits were to specialists?
_____ 3D. Total Visits

4. DENTIST VISITS: About how many times has the person been to the dentist in the past year?
_____ 4A. Number of times for exams, cleaning, and general preventive work
_____ 4B. Number of times for major work, surgery, or emergency situations
_____ 4C. Total Visits

5. EMERGENCY ROOM VISITS: About how many times in the past year has the person gone to a hospital emergency room?

_____

6. HOSPITAL ADMISSIONS: How many times in the past year has the person been admitted to a hospital for any reason?

_____

7. How easy is it to find medical care for this person?
        1 Very Difficult
        2 Difficult
____   3 About Average
        4 Easy
        5 Very Easy

8. RESPONDENT OPINION: Overall, how good is this person's health care?
        1 Very Poor
        2 Poor
_____   3 Fair
        4 Good
        5 Excellent

Abilities, Before and Now:
Before Self-Determination and Now (During The Past 4 Weeks)

Instructions
a) This information is to be obtained <u>BY INTERVIEW</u> with whoever knows this person best on a day to day basis. As a general rule, it is not comfortable or appropriate to ask these items of the person directly.
b) Please record the person's <u>highest</u> observed ability on each item.
c) Consider only what the person <u>DOES</u> do, <u>NOT</u> what the person "can" do or "could" do or "might be able to" do. <u>We want no speculation</u> - only observed, actual capabilities.
d) Count "typical" behavior, that is, behavior that is performed at least 75% (three fourths) of the time.
e) Count capabilities if done with <u>VERBAL</u> assistance, but <u>NOT</u> those done with <u>PHYSICAL</u> assistance.
f) Any item can be left blank if for some reason it is not applicable, irrelevant, or the person's capabilities are unknown.

BEFORE means before Self-Determination began for this person (or as long ago as the respondent can recall)
NOW means within the past 4 weeks

BEFORE	NOW	Ability Rating
		1. Word Usage (with or without adaptive equipment) 0 No use of words (or has no access to adaptive equipment) 1 Uses simple (one-syllable) words and associates words with appropriate objects 2 Uses complex words and associates words with appropriate objects, but has limited vocabulary 3 Has a broad vocabulary, understands meaning of words and uses them in appropriate contexts
		2. Expressive Language (with or without adaptive equipment) 0 Makes no sounds (or has no access to adaptive equipment) 1 Makes sounds but says no words 2 Says simple words 3 Says two-word sentences ("I go," "Give me, "etc.) 4 Says sentences of three or more words 5 Carries on basic conversation 6 Carries on more complex conversation
		3. Food preparation 0 Does not prepare food 1 Prepares simple cold foods (sandwich, cold cereal, etc.) 2 Cooks simple foods (eggs, soup, frozen dinners, etc.) 3 Cooks more complex foods and/or prepares complete meal
		4. Personal Hygiene (Bathing, washing, brushing teeth, grooming, and behaviors specifically related to gender and age, e.g., shaving, hair care, menses, use of deodorant) 0 Does not tend to own personal hygiene or is uncooperative 1 Cooperative, but needs physical assistance in most areas 2 Cooperative, but needs physical assistance in some areas 3 Needs frequent verbal prompting in some areas 4 Needs occasional verbal prompting in some areas 5 Takes care of most hygiene needs independently 6 Completely independent in personal hygiene
		5. Dressing 0 Does not put on any clothing by self 1 Cooperates in putting on clothes (raises arms, etc.) 2 Puts on some clothing by self 3 Puts on all clothes but does not tie shoes, close all fasteners or attend to other details 4 Dresses self completely including all fasteners and other details
		6. Household Chores 0 Does not do household chores 1 Attempts household chores but needs considerable assistance 2 Does household chores, but needs prompting 3 Does household chores independently
		7. Basic Medical Self-Help (first aid, non-prescription medication) 0 Does not display any medical self-help skills 1 Seeks aid in treatment of minor injuries 2 Performs simple first aid tasks (applies bandages, ice to a burn) 3 Has basic medical self-help skills and uses non-prescription medications (aspirins, etc.) appropriately

		8. Sense of Direction
		    0 Demonstrates no sense of direction
		    1 Needs prompting or other assistance to keep from getting lost
		    2 Sometimes (less than 50% of the time) moves about independently in unfamiliar settings, finding and learning own way
		    3 Often (over 50% of the time) moves about independently in unfamiliar settings, finding and learning own way
		    4 Reliably (over 90% of the time) moves about independently in unfamiliar settings, finding and learning own way

		9. Transportation About Community
		    0 Does not get around community
		    1 Gets around the community only with major assistance and/or accompaniment
		    2 Gets around the community with some assistance
		    3 Gets around the community with minor assistance
		    4 Gets around the community independently

		10. Money Handling
		    0 Does not use money (or has no access to money)
		    1 Uses money but unable to provide appropriate amount (gives 10 cents to purchase item in store, etc.)
		    2 Uses money, but does not usually make and/or count change correctly
		    3 Adds coins of various denominations, makes and/or counts change to $1
		    4 Makes and/or counts change in any amount

		11. Purchasing
		    0 Does not make purchases (or has no access to money)
		    1 Identifies items desired to purchase, but does not make purchase
		    2 Makes purchases with major support and/or coaching
		    3 Makes purchases with minor support and/or coaching
		    4 Makes purchases independently

		12. Ordering Food in Public (including with visual aids)
		    0 Does not order food at public eating places
		    1 Orders snacks (ice cream, hot dogs, tacos, etc.)
		    2 Orders simple meals (hamburgers and fries, tacos and beans, etc.), may require assistance
		    3 Orders complete meals independently

		13. Associating Time with Events and Actions
		    0 Does not associate events and actions with time
		    1 Associates regular events with morning, noon, or night
		    2 Associates regular events with a specific hour (dinner is at six)
		    3 Associates time with events in past, present and future (meeting is at six tomorrow)

		14. Handling Emergencies (police, medical help, fire help, emergency room services, mental health help)
		    0 Has not handled any emergencies of this kind
		    1 Has handled emergencies, but with assistance
		    2 Has handled emergencies, but not always appropriately
		    3 Has handled emergencies independently and appropriately

Adjustment And Challenges, Before and Now:
Before Self-Determination and Now (During The Past 4 Weeks)
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This information is to be obtained <u>BY INTERVIEW</u> with whoever knows this person best on a day to day basis. As a general rule, it is not comfortable or appropriate to ask these items of the person directly.

BEFORE means before Self-Determination began for this person (or as long ago as the respondent can recall)
NOW means within the past 4 weeks

Problem Severity <u>Before</u> 0=None 1=Mild 2=Moderate 3=Major 4=Severe	Problem Severity <u>Now</u> 0=None 1=Mild 2=Moderate 3=Major 4=Severe		**Adjustment and Challenge Area**
		1	Self-Injury
		2	Assaulting Others
		3	Threatening Others
		4	Damaging Property
		5	Screams/Cries/Yells Inappropriately
		6	Unusual/Repetitive/Stereotyped Behaviors
		7	Social Withdrawal
		8	Depressive Symptoms
		9	Suicidal Actions, Tendencies, Thoughts
		10	Hallucinations/Delusions
		11	Poor Grooming/Cleanliness
		12	Eating Disorders
		13	Hyperactivity/Mania
		14	Anxiety/Panic
		15	Inappropriate, Illegal, Or Dangerous Sexuality
		16	Substance Abuse
		17	Stealing
		18	Lying
		19	Setting Fires
		20	Running Away

Integrative Activities

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ABOUT HOW MANY TIMES did this person do each of the following in the PAST MONTH? ONLY COUNT ACTIVITIES WHEN THE PERSON WAS IN THE PRESENCE OF NON-DISABLED CITIZENS. (**Rough estimates are fine.** If the past month was not typical, ask about the average month during the past year. Write DK if "Don't Know.")

	Before (Past Month)	
1.		Visit with close friends, relatives or neighbors
2.		Visit a grocery store
3.		Go to a restaurant
4.		Go to a place of worship
5.		Go to a shopping center, mall or other retail store to shop
6.		Go to bars, taverns, etc.
7.		Go to a bank
8.		Go to a movie
9.		Go to a park or playground
10.		Go to a theater or cultural event (including local school & club events)
11.		Go to a post office
12.		Go to a library
13.		Go to a sports event
14.		Go to a health or exercise club, spa, or center
15.		Use public transportation (May be marked "N/A")
16.		Other kinds of "getting out" not listed above

17. ACCESS TO TRANSPORTATION: If this person wanted to go somewhere on the spur of the moment (beyond walking distance), how many times out of 10 would he/she be able to? If this person does not communicate such wants, phrase the question as "If someone unpaid wanted this person to be able to go somewhere on the spur of the moment ...." Count only trips that are within 1 hour of home.

BEFORE: _____ times out of 10

Connections with Family and Friends

1. **Involvement of Relative(s):** <u>About</u> how often do **any** relatives have the following kinds of contact with this person? (Accept times per week, or per month, and convert to approximate number of times per year.)

_____ **Check here if person lives with relatives – then score the items below for all <u>other</u> relatives.**

About how many times in the **past year**? (Zero if none)

_____ 1a. Telephone calls (including talking with staff)

_____ 1b. Mail and email

_____ 1c. Relative visits person here at this home

_____ 1d. Person goes out with relative(s)

_____ 1e. Program Planning Meetings

_____ 1f. Consent for medical care

2. **Number Of Friends**: <u>About</u> how many people in this person's life would you describe as friends? Do not count mere acquaintances (people one might say "Hi" to, or wave to, but with whom there is no other interaction). Friends might include housemates, co-workers, schoolmates, other people with disabilities served by the residential or day program agency, direct care workers, case managers, support coordinators, therapists, churchgoers, neighbors, merchants (workers in any commercial store), letter carriers, law officers, advocates, guardians, etc.

_____ friends

Close Friends Scale

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This table is intended to get at the types and characteristics of a few of the person's closest friendships.

- A "close friend" is anyone the person (or whoever knows the person best) defines that way.
- If there are fewer than 5 close friends, just describe however many there are.
- If there are close friendships with more than 5 people, please try to count only the closest 5.
- A relative can be a friend, but contacts with relatives have already been described above, so only include a relative here if the person or the respondent feels it is important to do so.
- This scale may be left empty – if the person has no close friends; please indicate this with a large "X."

Initials or code:	Relationship (Present or Former) 1=Relative 2=Staff of home 3=Staff of day program, school, or job 4=Other paid (Case manager, nurse, etc.) 5=Housemate 6=Co-worker or schoolmate 7=Neighbor 8=Merchant 9=Other	Gender of this friend 1=Female 2=Male	Does this friend have a disability? 0=No 1=Yes 9=D/K	About how long has the person known this friend? (Years - use fractions and decimals if needed, as in 2.5 years, or 2 ½ years) (999=D/K)	Is this friend involved in planning meetings, PCP, or circles? 0=No 1=Yes, minor 2=Yes, moderate 3=Yes, major	About how many times has the person had contact with this friend, in the past four weeks (28 days)? For people seen several times every day, such as staff of the home, just enter 28.
1						
2						
3						
4						
5						

Access to Supports Inventory
Provided Via the Home, OR the Job or Day Program
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INSTRUCTIONS
- First, find out whether each service is received by the person..
- Then get an estimate of how satisfied they are with each service on a scale of 1 to 5.
- Then have the respondent rate the importance to him/her of receiving each of the services..

Are you receiving this service?	How satisfied are you with the amount of each service received?	How important is receiving this service to you?	
0=No 1=Yes	1=Not at all 2=Hardly 3=Somewhat 4=Mostly 5=Completely	1=Not at all 2=Hardly 3=Somewhat 4=Mostly 5=Completely	**Type of Support**
1A	1B	1C	1 BASIC SELF-CARE SKILLS Teaching, not just helping; including hygiene, dressing, eating, domestic skills
2A	2B	2C	2 COMMUNITY SKILLS Formal programs to teach shopping, transportation, handling emergencies, etc.
3A	3B	3C	3 APPROPRIATE SOCIAL BEHAVIOR Manners, interpersonal skills, etc.
4A	4B	4C	4 COGNITIVE SKILLS Letters, numbers, shapes, colors, reading, writing, arithmetic
5A	5B	5C	5 OCCUPATIONAL THERAPY Delivered, designed, or supervised by an Occupational Therapist
6A	6B	6C	6 PHYSICAL THERAPY Delivered, designed, or supervised by a Physical Therapist
7A	7B	7C	7 COMMUNICATION, SPEECH, & HEARING THERAPY Formal programs designed to improve communication abilities (devices included)
8A	8B	8C	8 RECREATION Learning ways to use leisure time
9A	9B	9C	9 PSYCHOTHERAPY OR COUNSELING Delivered directly by a trained therapist
10A	10B	10C	10 SEXUALITY EDUCATION, OR COUNSELING Teaching person how to make safe and rewarding choices
11A	11B	11C	11 SPECIALIZED TRANSPORTATION PROGRAM Contracted transportation service, not including paratransit
12A	12B	12C	12 PERSONAL CARE ATTENDANT OR AIDE Providing help with physical needs
13A	13B	13C	13 PROGRAMS TO REDUCE CHALLENGING BEHAVIOR Systematic reinforcement programs of any kind
14A	14B	14C	14 OTHER What have you bought that you couldn't have without consumer direction?

Individualized Practices Scale

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INSTRUCTIONS
1) Please complete each item by interviewing the respondent (staff person or other caregiver).
2) Ask questions in this form: For item #1, "How is waking up handled on weekends and holidays?" Probe the response if necessary, and complete the item according to the answers.
3) Omit this scale in an individual home, a foster home, or a family home.

Weekend/Holiday Schedule

1. Waking time
   - 2 Flexible - people get up at different times
   - 1 Fixed - with exceptions
   - 0 Fixed - same for all

2. Bed time
   - 2 Flexible - people go to bed at different times
   - 1 Fixed - with exceptions
   - 0 Fixed - same for all

3. Dinner time
   - 2 Flexible - people can eat at different times
   - 1 Fixed - with exceptions
   - 0 Fixed - same for all

4. TV, Radio, and Music times
   - 2 Flexible - people watch/listen as individuals
   - 1 Fixed - with exceptions
   - 0 Fixed - times are set for all people by rules

Weekday/Workday Schedule

5. Waking time
   - 2 Flexible - people get up at different times
   - 1 Fixed - with exceptions
   - 0 Fixed - same for all

6. Bed time
   - 2 Flexible - people go to bed at different times
   - 1 Fixed - with exceptions
   - 0 Fixed - same for all

7. Dinner time
   - 2 Flexible - people can eat at different times
   - 1 Fixed - with exceptions
   - 0 Fixed - same for all

8. TV, Radio, and Music times
    - 2 Flexible - people watch/listen as individuals
    - 1 Fixed - with exceptions
    - 0 Fixed - times are set for all people by rules

General Activities

9. Going to work or day program
    - 2 Most people go to different jobs/day programs
    - 1 Some people go to the same jobs/day programs
    - 0 All people go to the same jobs/day programs
    - 9 N/A

10. Recreational trips (malls, parks, sports, walks, etc.)
    - 2 Usually as individuals or pairs (1 or 2 people with or without staff)
    - 1 Sometimes in groups, sometimes as individuals or pairs
    - 0 Always in groups
    - 9 N/A

11. Shopping for food
    - 2 Usually as individuals or pairs (1 or 2 people with or without staff)
    - 1 Sometimes in groups, sometimes as individuals or pairs
    - 0 Always in groups
    - 9 N/A

12. Doctor, dental, psychiatric, or other health care appointments
    - 2 Usually as individuals or pairs (1 or 2 people with or without staff)
    - 1 Sometimes in groups, sometimes as individuals or pairs
    - 0 Always in groups
    - 9 N/A

13. Restaurants
    - 2 Usually as individuals or pairs (1 or 2 people with or without staff)
    - 1 Sometimes in groups, sometimes as individuals or pairs
    - 0 Always in groups
    - 9 N/A

14. Worship
    - 2 Usually as individuals or pairs (1 or 2 people with or without staff)
    - 1 Sometimes in groups, sometimes as individuals or pairs
    - 0 Always in groups
    - 9 N/A

15. Birthdays
    - 2 Celebrated with individual ceremonies, parties, and/or gifts
    - 1 Sometimes in groups, sometimes as individuals
    - 0 Always in groups, e.g., all June birthdays in one party
    - 9 N/A

Home Physical Quality Scale
From Moos, Lemke, & Mehren, 1979, MEAP;
Modified by Temple University, 1983
Revised and Copyright © J.W. Conroy 1994, 1997

INSTRUCTIONS:
1) Not to be used in an independent living or family home setting.
2) This section is to be completed in private, after a tour of the home.
3) Avoid giving the impression of "taking notes" during the tour.
4) Some of the judgments may seem subjective, but please try to give ratings according to the concept of an "American average" home.

SECTION 1: EXTERNAL

1. As a neighborhood, how does the area around this home look?
>   3 Very pleasant and attractive
>   2 Mildly pleasant and attractive
> _____ 1 Ordinary, perhaps even slightly unattractive
>   0 Unattractive, slum-like

2. How attractive are the home's grounds?
>   3 Very attractive - as nice as, or nicer than, the grounds of the surrounding homes
>   2 Somewhat attractive
> _____ 1 Ordinary
>   0 Unattractive - the grounds stand out as being "different" and less attractive

3. How attractive is the building?
>   3 Very attractive - attractive design, excellent maintenance
>   2 Somewhat attractive
> _____ 1 Ordinary
>   0 Unattractive - building is deteriorated or unattractive

SECTION 2: ROOM BY ROOM

4. Orderliness/clutter
>   3 Neat - living spaces are very orderly
>   2 Some disarray
>   1 Cluttered
>   0 Very cluttered - furniture and other objects are in disarray
>   9 No such room at this residence

LIVING ROOM OR DAY ROOM	DINING ROOM	BEDROOMS	KITCHEN	BATHROOM

5. Cleanliness
>   3 Very clean
>   2 Clean
>   1 Dirty
>   0 Very dirty
>   9 No such room at this residence

LIVING ROOM OR DAY ROOM	DINING ROOM	BEDROOMS	KITCHEN	BATHROOM

6. Condition of furniture
   3 Excellent condition - like new, well-kept
   2 Good Condition
   1 Fair Condition
   0 Deteriorated - old and in poor repair
   9 No such room at this residence

LIVING ROOM OR DAY ROOM	DINING ROOM	BEDROOMS	KITCHEN	BATHROOM

7. Window areas
   3 Many windows
   2 Adequate windows
   1 Few windows
   0 No windows
   9 No such room at this residence

LIVING ROOM OR DAY ROOM	DINING ROOM	BEDROOMS	KITCHEN

8. Odors
   3 Fresh - air is fresh and pleasant
   2 Neutral or unexceptional
   1 Slightly objectionable
   0 Distinctly objectionable - unpleasant odors are apparent
   9 No such room at this residence

LIVING ROOM OR DAY ROOM	DINING ROOM	BEDROOMS	KITCHEN	BATHROOM

SECTION 3: OVERALL

9. Variation in decor of peoples' rooms (apartments.)
   3 Distinct variation - decor varies from room to room
   2 Moderate variation
   1 Little variation
   0 Identical - little or no variation

10. Personalization of peoples' rooms (apartments.)
    3 Much personalization - most of the furnishings and objects in the rooms belong to the individual
    2 Some personalization
    1 Little personalization
    0 No personalization is evident

11. Overall physical pleasantness of the home
    3 Quite pleasant
    2 Pleasant
    1 Somewhat unpleasant
    0 Distinctly unpleasant

12. Neighborhood safety impressions
    3 Very safe neighborhood
    2 Reasonably safe neighborhood
    1 Somewhat unsafe neighborhood
    0 Distinctly unsafe neighborhood

Visitor's Subjective Impressions

1. How happy do you think this person is?

0	1	2	3	4	5	6	7	8	9	10
Very Unhappy					In Between					Very Happy
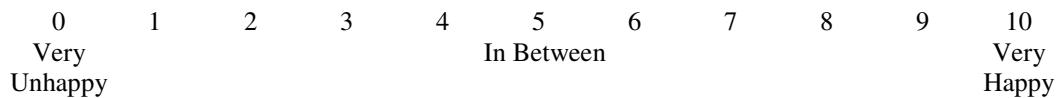
2. What is the quality of staff-consumer interactions?

0	1	2	3	4	5	6	7	8	9	10
Cold, impersonal					Neutral					Warm, personal
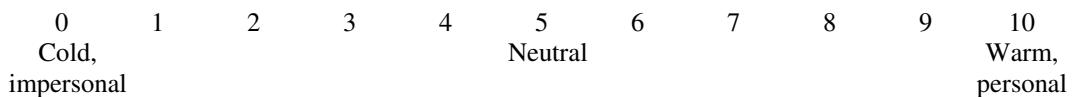
3. What is the quality of consumer-consumer interactions?

0	1	2	3	4	5	6	7	8	9	10
Unfriendly					Tolerant					Friendly
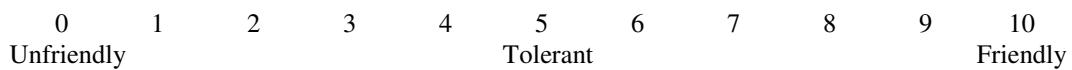
4. Staff attitudes about power and control issues (sharing power and choices with person and unpaid allies).

0	1	2	3	4	5	6	7	8	9	10
Grossly Over-Controlling					In Between					Highly Supportive of Choice-making
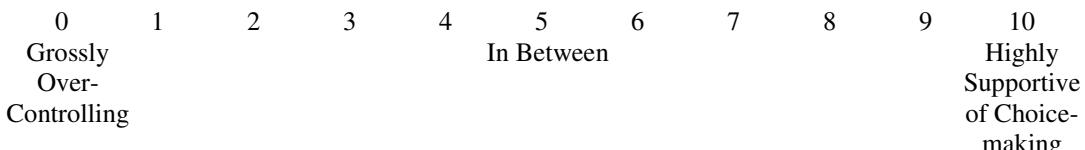
5. If you had a close relative with a major disability, how would you feel about him or her living in this home?

0	1	2	3	4	5	6	7	8	9	10
Extremely Negative					Neutral					Extremely Positive

6. Was there anything exceptionally NEGATIVE about this home that you feel it is important to describe?

7. Was there anything exceptionally POSITIVE about this home that you feel it is important to describe?